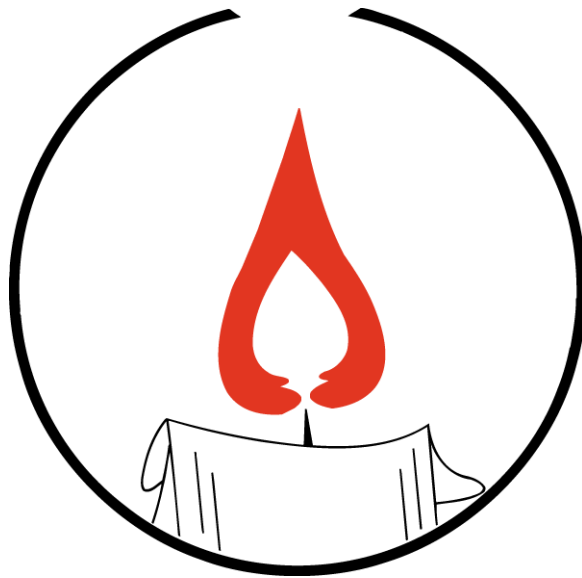


**ONTARIO PALLIATIVE CARE
ASSOCIATION**



ANNUAL REPORT

January 1, 2008 to December 31, 2008

2008 Executive and Board of Directors

Executive

PRESIDENT	Chris Sherwood, Palliative Pain & Symptom Management, HNHB CCAC
PAST PRESIDENT	Patricia Van Den Elzen, Consumer
VICE PRESIDENT	Lesia Wynnchuk, Consultant, Palliative Medicine, Sunnybrook Hospital
TREASURER	Patricia Van Den Elzen, Consumer
SECRETARY	Barb Linkewich, VP Health Services, Meno Ya Win Health Centre
MEMBERSHIP	Karen Fisher, Palliative Services & Wellness Coordinator, Hospice Wellington

Regional Representatives

Erie St. Clair (LHIN 1)

Sharon Allen, Nurse Practitioner Palliative Care, Hotel Dieu Grace Hospital

South West (LHIN 2)

Marie Palmer, Pain & Symptom Consultant/Educator Grey Bruce, St. Joseph's Health Care, London

Waterloo Wellington (LHIN 3)

Karen Fisher, Palliative Services & Wellness Coordinator, Hospice Wellington

Hamilton Niagara Haldimand Brant (LHIN 4)

Lesley Hirst, RN, MSCS (C), MN (C), College of Nurses

Central West (LHIN 5)

Amanda MacLennan, CNS Palliative Care, William Osler Health Centre

Mississauga Halton (LHIN 6)

Alison Powell, Case Manager, Mississauga Halton CCAC

Toronto Region (LHIN 7)

Diane Williams, Clinical Nurse Specialist/Nurse Practitioner, St. Michael's Hospital

Central (LHIN 8)

Carol Ford, Nurse Educator

Central East (LHIN 9)

Theresa Morris, PC Nurse Consultant/Manager, Peterborough Regional Health Centre

South East (LHIN 10)

Joan Schwarze, PPS Coordinator, Hamilton Niagara Haldimand Brant CCAC

Champlain (LHIN 11)

Debbie Gravelle, Manager, Regional Palliative Care Community Services

North Simcoe Muskoka (LHIN 12)

Vivian Papaiz, Palliative Pain & Symptom Consultant, Victorian Order of Nurses

North East (LHIN 13)

Elaine Klym, Resident Care Coordinator, Maison Vale Inco Hospice

North West (LHIN 14)

Marg Poling, Palliative Pain & Symptom Consultant, North Western Ontario CCAC

Community Members

Julie Darnay, Director, HNHB Hospice Palliative Care Network
Deborah Lavender, Executive Director, Hospice Association of Ontario

Liaison - OMA Palliative Care Section

[Position Open]



President's Report

As I have been considering what to put in this year's President's report, I realize how the process of crafting this document necessitates taking a moment to pause and thoughtfully reflect on both our work and issues external to our association that impact on our efforts – the State of the Union, so to speak. But, as I use the term "State of the Union", I think on the concept of the so-called "Union", only to question the extent to which we have one. As an association, we have a core membership that is certainly "unified." However, can the same be said of the hospice palliative care community within Ontario, of which the Ontario Palliative Care Association (OPCA) is one part?

At least as far as OPCA is concerned, perhaps it is worth starting off this report by considering how we as an organization are doing. The OPCA continues to try to accomplish what it can with its limited means. We have one very dedicated support person – Ellen Power – who in exemplary fashion keeps the day-to-day operations functioning, a committed Board of Directors to oversee the work of the organization and a diverse membership, which like the roots that feed the rest of a plant, so too is our membership our roots that sustain us. From the outside I sometimes wonder whether or not others might think that we are bigger than we are, but it is quite clear from the description I just provided that we are not very big at all, at least not big in numbers of staff who might conduct the work of an organization. We are an association of very dedicated individuals who recognize that we are able to make more of a difference collectively than those same individuals would be able to do so on their own.

Some might argue that we as an association exist to serve our members and that unless we are doing this, we are not fulfilling our obligation to them. I question whether this is indeed true and whether or not our members are instead more altruistic than this and concerned more with participating in a community of people who have

a higher calling – to serve others. And, what better demonstration of proof to support that this is true than what our vision states: quality end-of-life care for all Ontarians. This is clearly a goal that extends beyond our membership and to all the people of Ontario.

So, to this end, how are we doing? What is the "State of the Association" and are we making the difference that we aim for? It is fair to say, that as a group of volunteers (other than Ellen Power, of course), there are significant limitations in our ability to accomplish the above-stated vision. Our financial situation this year unfortunately did not allow us to retain the services of Barry Ashpole and Associates, and thus whatever communications strategies we may have otherwise had have been limited. However, it would be presumptuous to conclude based on limited communications that OPCA has not been working.

Though, as I consider the work of OPCA, I must quickly acknowledge that our work is becoming so inextricably intertwined with the work of other organizations that I cannot talk much about OPCA in isolation of these – most notably the Hospice Association of Ontario (HAO) and the Provincial End-of-Life Care Network (PEOLCN). Even as I write this note, the OPCA and HAO are both preparing to participate in an advocacy workshop that the PEOLCN has coordinated with the Canadian Hospice Palliative Care Association. Interestingly, OPCA and HAO, in conversation with PEOLCN mutually agreed to support their efforts to organize the event and to work with them to do so. This decision was reached in part because of the fact that our three organizations meet on a regular basis through our respective leaders and discuss issues of mutual interest and areas for collaboration. This degree of collaboration is not something we would have seen several years ago and therefore must be recognized as some of the very work that has been occurring and a very positive change for Ontario.

Last year, I noted that OPCA extended an invitation to Deborah Lavender, the Executive Director of HAO, to sit as a member of our Board. We purposefully did not want any quid pro quo and instead we extended the invitation

because it was the right thing to do. Since then, another vacancy on our Board opened that would enable one of the Co-Chairs of the PEOLCN to participate and so now Julie Darnay likewise also sits as a member. And, since then, HAO has reciprocated and extended an invitation to me, as President of OPCA, to sit on their Board. These cross appointments provide opportunities to understand how we can support one another and to ensure that where we might have otherwise innocently overlooked areas for potential collaboration, we now have checks and balances to minimize this risk.

Since our last Annual General Meeting, there have been other major advances, advances that I think we can be immensely proud of. Without question, obviously one of the most poignant is the change that we have made with our conference. This year's conference will no doubt be one that will make a long lasting impact on those who attend. Without question, the anticipation around this event has been palpable. At the same time, yet again, we cannot talk about the positives with this year's conference, without making mention of the Humber Institute of Technology and Advanced Learning. The leaders from Humber associated with the former provincial Conference on Palliative and End-of-Life Care could not have been more gracious and more helpful. On behalf of the OPCA, again we would like to extend our sincerest thanks and appreciation to Humber, and specifically to Teresa Sottile, Pamela Richardson and Carolynne Fletcher. As well, I would be remiss if I did not acknowledge the incredible efforts of the members of the current Planning Committee, both OPCA's – Lesia Wynnchuk (Co-Chair), Amanda MacLennan and Karen Fisher and HAO's – Beth Ellis, Maureen Talbot and Brent Charette, and the Conference Planner, Denise Larocque. The efforts of this group to put this conference together within a very compressed timeline (six months) has been nothing short of remarkable.

Yet, while indeed the conference is a tremendously positive change for our organization, I would suggest to you that this change is symptomatic of a much bigger change and a change that holds much more promise than any conference could in and of itself. This does not diminish in any way whatsoever from the conference. Instead, again speaks to the degree of collaboration and partnership that is such a

radical transformation for OPCA and HAO. These are the first significant expressions of our new working relationship, but certainly not the last.

Another area of progress specific for OPCA has been with the Certification of Expected Death Task Force. This Task Force approved a Final Document that the signing authorities of each of the respective Task Force member organizations signed. The signatures were on two Motions as confirmation of the consensus that we acquired. Following this, the consensus document itself and a letter were submitted to the Honourable Minister Caplan seeking the support of the Ministry of Health and Long Term Care. While the initial response was not quite what we would have hoped for, we are very hopeful that significant progress is just around the corner and hopefully this time next year we will be able to report on the next stage of development.

It is important that I recognize the members of our Board who have left this year. Stepping down this year were: Lesley Hirst, Dale Massender, and Kelly Emerson, I would like to extend my personal thanks to each of these individuals for their commitment and support of OPCA over the years. It has been a pleasure working with each one of you.

In closing, I would suggest that the biggest changes over the last year have been the forging of relationships. Who is the beneficiary of this work? While certainly our members are, there is no question that the most potential for benefit over time is to all Ontarians who will have the opportunity to reap the rewards that come from organizations who understand that together they are greater than the sum of their parts. So, in asking the question, "What is the state of our union?" In a rather poetic way, it is perhaps dependent on who you consider to be included in this "union". Rather than attempt to answer in specifics what is better left to a poem's reader to interpret, it is fair to say that it is very good; it has a long way to go; it holds the hope and promise for much more; It is not there yet...



Chris Sherwood
President, Ontario Palliative Care Association

History of the Ontario Palliative Care Association

On November 12, 1980, the Palliative Care Work Group, Toronto chairman Dr. Larry Librach, chaired the first informal meeting of representatives from all parts of Ontario. The enthusiasm generated by this meeting led to the formation of the Ontario Palliative Care Association and our first official meeting was held May 11, 1981 at Toronto Grace Hospital with 27 in attendance. The first executive elected were Dr. Larry Librach, Sister Judith Souliere, Dr. John Scott, and Dr. Ann Thomas. The initial tasks taken on by the executive were:

- affiliation with the Ontario Hospital Association (accomplished November 1981)
- funding of palliative care (on-going)
- educational events (on-going)
- assisting in the development of Guidelines and Standard for Palliative Care in Ontario (on-going)
- development of a manual of palliative care programs and members (on-going)
- development of a newsletter (established in 1982 and on-going)

During 1984/85, the Regional Groups were developed to expand our provincial representation. We currently have 7 Regions across Ontario and two representatives from each Region (three representatives from the North Region) sit on our Board of Directors.

In 1989, we received our Letters Patent and were incorporated as a registered charitable organization.

Our membership has grown from 57 at our first Annual General Meeting in 1982, to over 300 currently and includes the full spectrum of individuals involved with and committed to palliative care in Ontario.

Definition of Hospice Palliative Care

Hospice palliative care aims to relieve suffering and improve the quality of living and dying.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

Source: A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Canadian Hospice Palliative Care Association, March 2002, page 17

Guiding Principles

Patient/Family Focused – As patients are typically part of a family, when care is provided the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

High Quality – All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality
- standards of practice that are based on nationally-accepted principles and norms of practice, and standards of professional conduct for each discipline
- policies and procedures that are based on the best available evidence or opinion-based preferred practice guidelines
- data collection documentation guidelines that are based on validated measurement tools.

Safe and Effective – All hospice palliative care activities are conducted in a manner that:

- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition
- complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organizations.

Accessible – All patients and families have equal access to hospice palliative care services:

- wherever they live
- at home, or within a reasonable distance from their home
- in a timely manner.

Adequately Resourced – The financial, human, information, physical and community resources are sufficient to sustain the organization's activities, and its strategic and business plans. Sufficient resources are allocated to each of the organization's activities.

Collaborative – Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership.

Knowledge-Based – Ongoing education of all patients, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

Advocacy-Based – Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and association, and the public is essential to increase awareness about, and develop hospice palliative care activities and the resources that support them. All advocacy is based on the Canadian Hospice Palliative Care Association's model to guide hospice palliative care.

Research-Based – The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

Source: A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Canadian Hospice Palliative Care Association, March 2002, page 19, 20

Role of the Ontario Palliative Care Association

Advocacy - We present a strong, proactive voice on issues specific to the provision and delivery of quality end-of-life care – professional education, standards of practice, government policy development and funding, and public awareness.

Education - We promote professional education of hospice palliative care providers through our support of an annual provincial hospice palliative care conference and offering educational bursaries.

Recognition – We recognize excellence in hospice palliative care with the annual Dorothy Ley Award of Excellence in Hospice Palliative Care, and support of hospice palliative care with the Outstanding Philanthropist Award.

Communication - Our newsletter is published three times per year and is distributed to our full membership plus organizations and individuals with an interest in hospice palliative care issues.

Partnerships – We maintain a close partnership with the Canadian Hospice Palliative Care Association and develop partnerships with other organizations to address specific issues as they arise.

Mandate

Our mandate is to further the provision of high quality, timely, and effective hospice palliative care to all Ontario residents through our activities in advocacy, education, awareness, communication, and partnerships.

Goals

To support our members by:

- Providing education development opportunities to facilitate communication
- Being a central resource for information
- Being a link between local, regional, provincial and national palliative care

To encourage the development and expansion of palliative care in Ontario by:

- Advocating the importance of palliative care through influencing government policy and funding
- Promoting standards in palliative care
- Participating in the evolution and implementation of standards
- Enhancing the work of OPCA
- Maintaining financial stability

The Provincial Charter for End-Of-Life Care

How we treat those who are dying in our community reflects who we are as a society. All Ontarians have the right to die with dignity, to have access to physical, psychological, bereavement and spiritual care, and to be granted the respect consistent with other phases of life.

As professional, volunteer and family representatives of Ontario's hospice palliative care community, we are committed to providing the best possible quality end-of-life care to Ontario residents and their families. Our goal is to optimize their quality of life and to minimize the physical and emotional suffering associated with this phase of life.

We endorse an integrated approach focused on the individual and their family and caregivers, accessible through hospice palliative care services in the local community and tailored to individual needs.

Our efforts to increase awareness and availability of quality and integrated end-of-life care run parallel to our collaboration with government, social agencies and other decision makers to develop innovative clinical, community and public policy strategies.

On behalf of the residents of Ontario whom we serve, we speak with a unified and cohesive voice, share information and resources and work through a coordinated network of partners from the voluntary, public and professional sectors.

OPCA Position Paper: Regional Home Palliative Care for Ontario

The Ontario Palliative Care Association (OPCA) strongly supports government initiatives to develop regional home palliative care programs throughout Ontario. We would like to bring forward a number of principles that we feel should govern the development of these programs:

1. The planning and implementation of these programs should follow the Model to Guide Hospice Palliative Care Based on Principles and Norms of Practice as identified by the Canadian Hospice Palliative Care Association. Since these standards are being used by the Canadian Council of Health Services Accreditation to accredit institutions and agencies including home care programs and by the Hospice Association of Ontario to set standards, the norms of practice will introduce a consistency in programming and make evaluation of programs consistent.
2. Wherever possible, interdisciplinary teams of health care professionals and volunteers should form the core of services. The nature of home palliative care requires a variety of skills and maximum support to patients and their families to stay at home as long as possible. The Community Care Access Centres should be provided with funding to support advance practice nurses, social workers with specialized palliative care skills and primary palliative care nurses. The funding for palliative medicine physicians to work with these teams should be through alternate payments programs and special consideration be given to models for rural and northern practices. Volunteer hospices should receive sufficient funding to support the training of volunteers to work as part of the regional teams.
3. Regional services should not consist of a loose coalition of institutions and agencies. These institutions and agencies should be bound by legal agreements to participate actively in the regional programs and be bound by service deliverables. In the best of all models, regional teams of secondary experts should stand on their own with clear lines of responsibility back to a management group that includes members of the public. In the best of all models, personnel on the teams would be hired by or seconded to the teams and be responsible to the teams for their clinical services.
4. There should be a single focus of access for services in each region although referrals may come from many sources.
5. A common chart in the home is required in order to standardize record keeping.
6. Common data must be collected in each region so that outcomes can be monitored effectively.
7. Specialized hospice palliative care teams must be present in each institution/hospital.
8. Specialized hospice palliative care teams must be available to support patients/residents in long term care facilities and community supportive housing.

Annual Ontario Provincial Conference

The Ontario Palliative Care Association enjoyed a long partnership with Humber College Institute of Technology & Advanced Learning in planning and producing the Annual Ontario Provincial Conference on Palliative & End-of-Life Care. As the world around us changes, our organizations must also adapt. It was therefore, with mixed emotions that we agreed to end our collaboration after the 2008 Conference.

Each of our organizations have deeply appreciated and respected the other, making this decision that much more difficult. Despite the end of our Conference partnership, Humber and OPCA intend to continue working together on other areas of shared interest.

We express our deep appreciation to past planning committee members, speakers who have shared their expertise, sponsors who have provided their support, volunteers who have given their time, and the delegates who have demonstrated their commitment to education and the ongoing enhancement of hospice palliative care.

The Board of Directors of OPCA especially extend their appreciation to Teresa Sottile, Conference Manager, Humber Corporate Education Centre, for her many years of dedication to our Conference. Teresa and her team gave us service above and beyond what would normally be expected of a Conference Manager. Her heart was truly with hospice palliative care, we thank her whole-heartedly, and wish her continued success in all aspects of her life.

Palliative Care Outstanding Philanthropist Award

This award is designed to recognize and show our appreciation for those individuals, families, corporations, foundations, and community and service organizations who best exemplify vision, financial support and dedication towards fostering the true spirit of palliative care in Ontario.

While the financial support offered by these philanthropists is important to our cause, it is the encouragement and validation of our efforts that means so much to us as individuals. They are truly the “unsung heroes” of palliative care in Ontario.

Honour Roll Recipients of the Palliative Care Outstanding Philanthropist Award

Knoll Pharma Inc. (1997)
Glaxo Wellcome (1998)
Saint Elizabeth Health Care Foundation (1999)
Parkwood Hospital (2000)
Peterborough Festival of Trees (2000)
Barrie Rose (2001)
Purdue Pharma Inc. (2003)
Care for Kids (Toronto) (2004)
Albert Latner (2004)
Stuart and Irene Lunn (2004)
Harold Wolfe & Phyllis Flatt (2006)
Margaret Anderson (2006)
Brockville's 30 Hour Telethon for Palliative
Care (2007)

Note: No award presented for 2002 and 2005.

Dorothy Ley Award of Excellence in Hospice Palliative Care

The late Dorothy Ley was one of Canada's first champions for quality care at the end of life. She brought a unique individuality to the field of hospice and palliative care, and maintained a highly visible and vocal presence during her distinguished career until her death in 1994. Dr. Ley was a pioneer and she broke new ground in fields of medicine and in health care in general.

The Dorothy Ley Award of Excellence, established in 1996, is a perennial reminder of her truly great legacy. Presented by OPCA, the Dorothy Ley Award of Excellence is awarded annually in recognition of an individual or team effort to advance and improve the quality of palliative and end-of-life care.

Nominations are made and endorsed by three individuals, one of who must be a current member of OPCA. The nominee is not required to be a member of OPCA. The Board appoints a Selection Committee to review the nominations and select the recipient based on predetermined criteria.

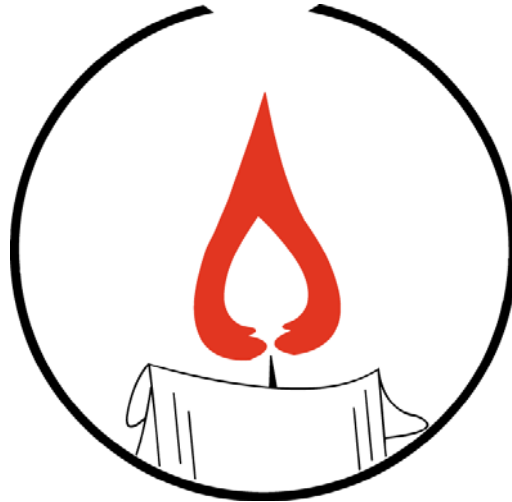
Honour Roll Recipients of the Dorothy Ley Award of Excellence In Hospice Palliative Care



Mary Vachon, RN, PhD (1996)
Reena McDermott, RN (1997)
Shari Douglas, RN (1998)
Frank Ferris, MD (1999)
Linda Bowring, MD (2000)
Ivan Stewart, MD (2001)
John Flannery, RN (2002)
Deborah Dudgeon, MD (2003)
Jean Echlin, RN, MScN (2004)
Maryse Bouvette, RN, BScN, MEd, CON(C),
CHPCN(C) (2005)
Charmaine Jones, MD (2006)
S. Lawrence Librach, MD, CCFP, FCFP (2007)

*Larry Librach accepts the award
from Chris Sherwood.*

ONTARIO PALLIATIVE CARE ASSOCIATION



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